No Time To Waste

New Routes Home

Professionals edition

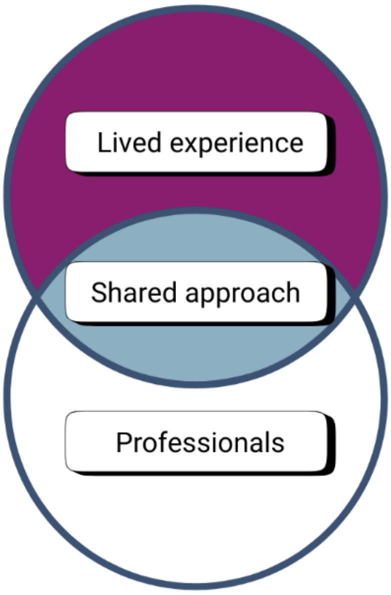
IMPACT
Improving Adult Care Together

A practical reflective toolkit focussing on approaches, power sharing, accountability and learning around long term hospital admissions and discharges for people with Learning Disabilities and Autistic People

Welcome

If you are here, you have taken a step towards learning and exploring how we can move on from approaches that are damaging and flawed. Whether you feel you have much power to influence change or not, we hope you will explore this resource and use it to reflect on the ways we can work together to create an effective reflective approach.

We have worked with a range of professionals and people with lived experience to coproduce two toolkits – one for professionals and one for individuals and families, these fit together to create a different way of working.



What is this and how do you use it?

This toolkit for professionals takes you through understanding how the system can get in the way for many people and walks you through an alternative approach that works.

If we are going to get the right answers we need to ask the right questions, understand what is important, and make the decisions that move us forward in the way that makes most sense to the person.

This is a framework to allow us to do that in a way that helps us –

- Start at the right place
- Work together in ways that make sense for everyone involved
- Equalise power and accountability
- Ask the right questions
- Have confidence to base action on analysis of what really matters and do more of the right things
- Move at the right pace
- Share our learning for next time

You can use it on your own and also as part of your team, encourage others involved to use it too and share your findings with each other.

In the green boxes there will be questions for you to reflect on and record as you go through, at the start, and as you progress through using it. Answer them quickly and honestly and as you progress through the toolkit, you will get a better understanding of your readiness, and what the barriers are, allowing you to make changes.

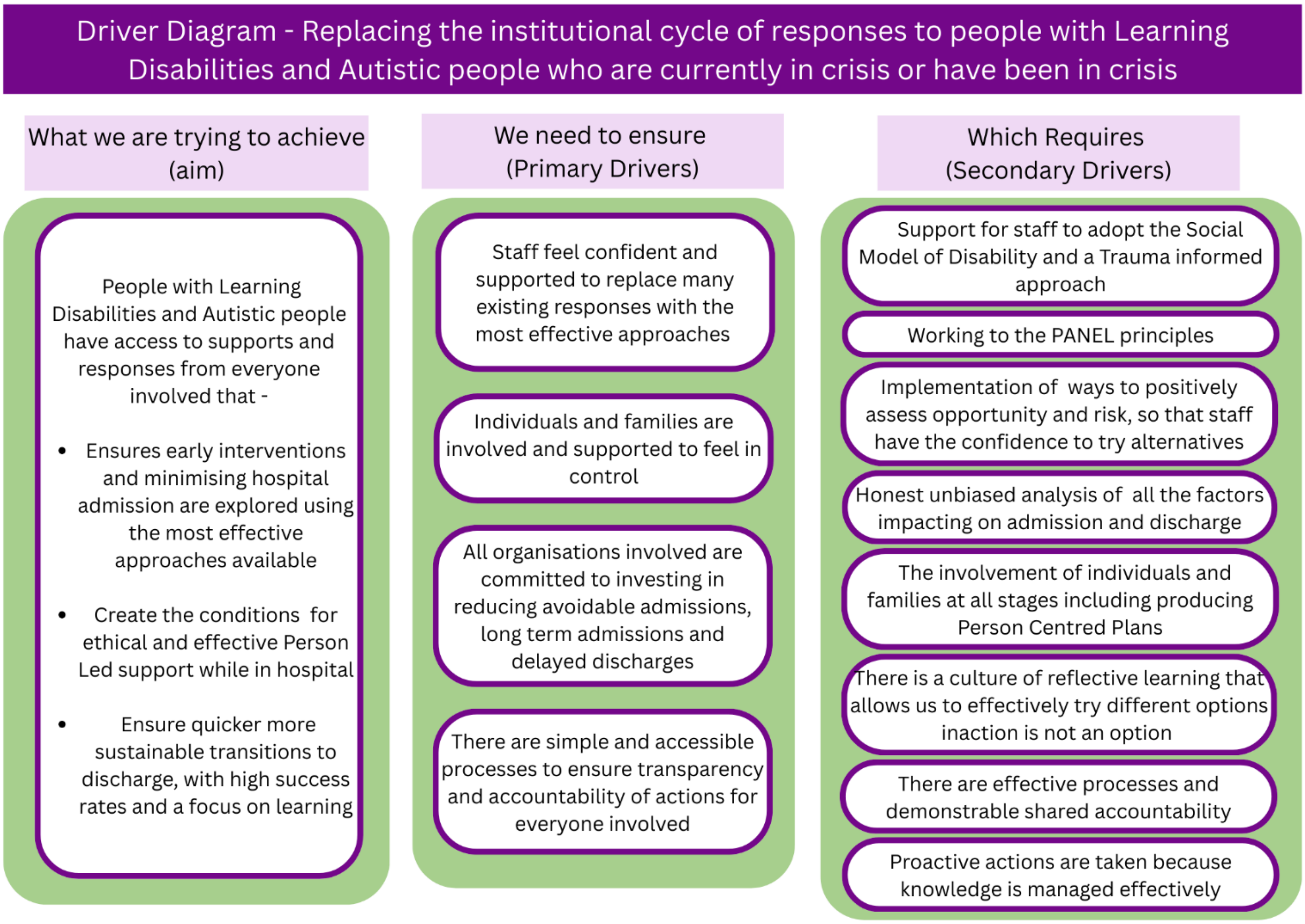
Contents

The first section is a practical self-assessment toolkit exploring different professional and organisational systems and responses and the impact of those approaches on the person and those around them.

The second section provides the reference material, case studies and related information. You can read this first if you want to, or you can refer to it at the end. The main point of the reference material is to provide detailed evidence of how and why we came to the conclusions and give examples to enhance your knowledge.

Drivers Diagram

How it fits together:



Driver Diagram - Replacing the institutional cycle of responses to people with Learning Disabilities and Autistic people who are currently in crisis or have been in crisis

What we are trying to achieve (aim)

People with Learning Disabilities and Autistic people have access to supports and responses from everyone involved that -

- Ensures early interventions and minimising hospital admission are explored using the most effective approaches available
- Create the conditions for ethical and effective Person Led support while in hospital
- Ensure quicker more sustainable transitions to discharge, with high success rates and a focus on learning

We need to ensure (Primary Drivers)

Staff feel confident and supported to replace many existing responses with the most effective approaches

Individuals and families are involved and supported to feel in control

All organisations involved are committed to investing in reducing avoidable admissions, long term admissions and delayed discharges

There are simple and accessible processes to ensure transparency and accountability of actions for everyone involved

Which Requires (Secondary Drivers)

Support for staff to adopt the Social Model of Disability and a Trauma informed approach

Working to the PANEL principles

Implementation of ways to positively assess opportunity and risk, so that staff have the confidence to try alternatives

Honest unbiased analysis of all the factors impacting on admission and discharge

The involvement of individuals and families at all stages including producing Person Centred Plans

There is a culture of reflective learning that allows us to effectively try different options inaction is not an option

There are effective processes and demonstrable shared accountability

Proactive actions are taken because knowledge is managed effectively

Background

The Coming Home Report [1]was published in 2018, highlighting the issue of inappropriate placements for people with learning disabilities and autistic people. Its Implementation Plan[2] aimed to make *'real change with out-of-area residential placements and inappropriate hospital stays greatly reduced'* by March 2024. Despite attempts to drive a change in pace and effectiveness of work with individuals in this situation, very little has changed for many people, since in many cases the same methods were being used, with some additional resources and scrutiny such as Dynamic Support Register meetings. These are important steps forward but need to be aligned with a different mindset and a substantial shift in accountability. The ability to create the shift in attitude and confidence to get substantially different results has been limited. Some areas sought to genuinely change the way they were approaching the situation, such as the Assertive Outreach Team in Renfrewshire, but these were not mainstreamed and are at risk of being removed despite their success. We need the whole system to shift to operate in this way with confidence or we always move at the pace of the slowest part of the system.

Many people with Learning Disabilities and Autistic people who get stuck in long stay hospital admissions or out of area placements find it to be a long and torturous road back to the community. The stress and trauma created by the mismatch between what the person needs and what the system provides can result in massively increased risk for the person, their family and for those supporting them.

How do we measure what actions have been taken to avoid a hospital admission? How do we measure progress, when supporting someone to leave long stay hospital? Ultimately, what do we learn from the decisions that we take, either at home or while in placements?

While people are stuck in hospital or inappropriate placements, we often do not focus enough on the person's quality of life, often taking away all the structure, all the connections, everything that gives the person's life

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[1] https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/

[2] https://www.gov.scot/publications/coming-home-implementation-report-working-group-complex-care-delayed-discharge/

meaning in the name of safety. With the right approach, this is avoidable, but even when we know this, it keeps happening.

How to complete this toolkit

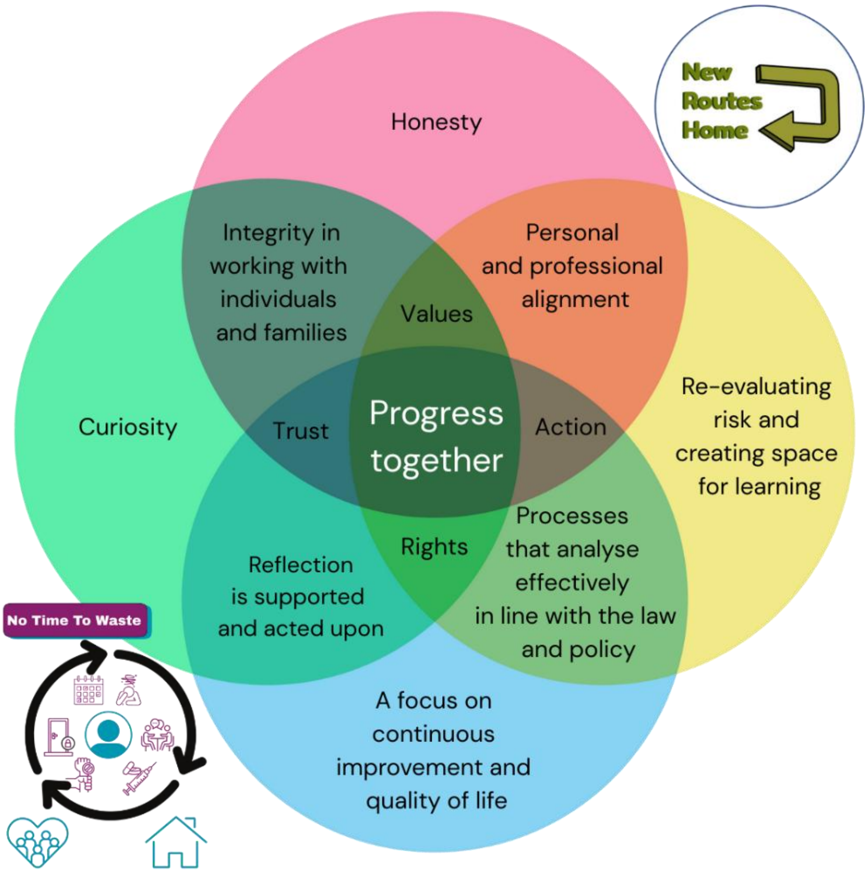
This a tool to facilitate reflection, learning and a better balance of the sense of opportunity and risk around the options available. It is aimed at increasing confidence to explore possible options together and reduce the sense of isolated responsibility.

We will be using Strengths Based Approaches and Trauma Informed practice. It is important to explore all the areas and avoid shortcuts by overlaying existing assessment work which may be deficit focused.

We have designed this as a two-part document. The first part is the assessment / reflection / learning section, which puts principles into practice. It looks at the organisational systems and responses, and the impact on the person and those around them, with input from everyone involved. The second part explores the methods we are using in more detail and provides the reasons behind this shift in approach as well as examples / case studies.

We are aware of the importance of any differences between what your individual awareness and tolerance for change is, and the organisation you work for. For each question, record any gap between what you can do within your role and what you would want to do. If you are an organisation signing up to be part of this process, we ask you to fully commit to the objectives indicated on the next page. We are not being prescriptive about how these are carried out, only that these feature openly in how you engage with your workforce around this issue, and that you are willing to share the outcomes from your learning.

The image below describes what we expect to see and experience when using the toolkits. If that is not happening, it should be reviewed with all involved.



In part two we will offer a set of statements that match our experience of different approaches taken at key points: pre-admission, in hospital, and in the community. Identify what elements of the first statement are present and then do the same for the second statement. Be careful to do it in a way that encourages open reflection and reduces any sense of blame. Avoiding the use of “I” and “you” when discussing actions and focus on whether the actions were effective at achieving their intended outcomes. Keep using it; as soon as we stop using this approach, we are at risk of going backwards.

Why?

There is a human and a financial cost of getting this wrong, by undertaking this process openly and exploring different ways forward together, you are reducing trauma for the person, their family, and staff expected to carry out overly restrictive regimes. In addition, the waste of resources associated with delayed discharges and overly institutional settings in the community is crippling financially.

How?

A focus on exploration rather than process, problem solving rather than problem listing, Asking - “what would it take?” vs “what is wrong?”.

When evaluating where we are when looking at a statement, everybody’s views need to be captured and explored. If we feel we met all the aspects of a statement, say why and give examples. If there is a difference of opinion, record why and try and identify how to move forward. The power shift we need relies on honesty, even if we don’t have all the answers.

Reflective questions

We start by asking ourselves these questions –

How well do we know the person? *Not how they behave under crisis.*

Is what we are doing working? and how do we know?

These are the most important questions to start with, because quite often we end up responding because that is what the system tells us to do, or what we know is not balanced and useful.

We need to ask - how do we understand what is important for the people we are supporting? *Even if we would struggle to provide it.* Get people together and ask what good looks like for the person. Don’t look for consensus, just gather information from a range of viewpoints, family and professional.

Explore whether you have evidence for the parts of the system that are getting the right results and write down evidence you have that supports what you think and anything else that challenges it. *Don’t take a fixed position.*

Is the approach that you are taking one that everyone is using, or just you? Think about creating a space to discuss what you are happy to share: *'I noticed this… I wondered if we should try that…can anybody suggest a way for us to…'*

This is about using reflection and analysis to support continuous improvement, not gathering evidence that only supports the position you are taking. If we aren't prepared to listen and learn from everyone, we will struggle to achieve meaningful change.

What are we focusing on?

Are we focusing on "presentation" and managing how the person behaves under stress? Or are we recording what we found out about the difference between what's important /what works for the person and what has been happening.

What is the gap in our understanding and approach between these different approaches?

Understand the difference between causation and correlation, and the level of detail in your analysis of what happened.

Be clear about what you record and how you come to any conclusions. We often see statements made which either miss context, or don't accurately separate the person from their behaviour under stress, this can make us go in the wrong direction when deciding what to do next.

What would help close the gap between our understanding and approach?

What would be an effective way to balance the risk and measure how ideas develop?

At this stage it is important to acknowledge professional boundaries, custom and practice and what feels safe to change.

What we record and how we act on it -

Jim is upset when his parents visit

We need to stop visits to keep everyone safe

Jim is upset when his parents leave, particularly if he doesn't know when the next visit will be

We need to think about how we structure visits and reduce anxiety about the next one

Organisational facilitators and barriers

Comfort zones –

We often have set ways of assessing risk, recording need and planning for discharge.

What is preventing accountability for any harm this causes?

Create a space where you are curious and questioning about the balance between opportunities / risk and how we measure progress.

If we ask the wrong questions it leads to the following cycle of flawed actions and analysis

The person is displaying unwanted behaviours

The emphasis is on reducing this behaviour through compliance in a place lacking many aspects of relationships, control and a homely environment

This is often attempted to be managed by reduced freedom (described as more of a controlled environment) and medication

The person either complies while still under stress or the restrictions continue to build

The person is either overwhelmed by the level of pressure to behave in the way that is expected or becomes becomes compliant through the use of medication, or the frustration and resistance continues to escalate further creating a false reputation

We should be asking the following

We strive to understand what works for the person (even if we can't provide it all) and we name everything that is causing potential harm

We act in a way that allows the person to trust us -
Logical changes at a pace they can cope with

We alter what we do to fit what works for the person, not expecting the person to change to suit us, and explain this in a way that helps the person feel in control

We check that what we are doing is working for the person, and if not we continue to change it in a planned way until we get it right focussing on quality of life as well as discharge

We work on the transition to community as quickly as possible recognising that expecting the person to behave in a positive way whilst under high stress is unrealistic and not in the person's interests

PART TWO

Understanding the Different Approaches

There are two distinct ways that systems and individuals respond to people in crisis:

Approach 1

Reports look at what has happened and base plans around how everyone can be confident that the person is able to cope in a series of situations leading up to them being admitted, often in a service / staffing structure based mainly on how they present in hospital. Evaluation is based on professional assessments mainly, starting with the idea that training and professional opinion is the key to progress.

The person must achieve milestones to be confident to go forward and there is a focus on reducing risk through managing access to activities and situations. In this model the person is expected to show changes in behaviour in response to a set of situations within expectations and restrictions placed on them. The person's life gets smaller and often impacts heavily on meaningful structure and important relationships.

Approach 2

We ask 'who is the person?' not 'what is the behaviour are we seeing?' We start with the understanding that we need to change to fit in with what the person and those closest to them are telling us. We find out what matters to them and honestly record how much of that has been well supported, leading up to their admission to hospital. We then try to ensure as much of the focus is creating consistency and trust by delivering as much of what is important to the person to show that we understand that the purpose to our work is the person feeling safe, listened to, and well supported. We don't spend time explaining why we couldn't provide what the person needed, instead focusing on acknowledging it and appreciating what we can learn to ensure we don't repeat those mistakes. Using this Person Centred model, we focus not on how the person needs to change while in a stressful environment, but how we can change what we do to be closest to what they need. We relentlessly focus on ways to minimise the anxiety, restrictions and avoid setting hoops for people to jump through.

In reality, most of what happens is a mix of the two.

When we feel powerless our response will be anger and frustration or hopelessness and depression. We need to recognise that there is a massive disparity in power, where professionals have the ability to pull out of plans and reset progress for a person at any stage. This results in everything happening at the pace of the slowest actions until we have every piece of the puzzle, with progress becoming fragile.

When risks feel significant, and power is not shared, it becomes easier to do nothing rather than professionals feeling a risk of blame if anything they change goes wrong.

This level of risk to professional accountability is not equitable to the pressure to acknowledge and be accountable for continuing to carry out actions which cause distress, reduce someone’s human rights and are preventable with another approach. A failure to recognise the impacts and do everything to counter those creates false barriers to progress.

There are a number of clear markers that determine both the likelihood of someone with a Learning Disability and / or an Autistic person being detained in long stay hospital or inappropriate out of area placement, and also the speed and effectiveness of planning for their return to the community.

One key focus will be on outcomes and learning; another will be exploring the power shift and accountability that should take place as a result of the questions we ask and our approach to the challenges we face.

We are emphasising a Human Rights and Trauma Informed approach which avoids blame, and asks us all to be really open and honest as work together on moving forward. By focusing on the right areas, we can avoid stalemates around what progress looks like and work together more effectively.

Don’t focus on actions you think you could take in this section - What do you notice and recognise about what has been said so far? Do you feel that there is acknowledgement this is happening? During the rest of the toolkit, identify when you or others are being able to follow this process and when you feel something is causing you to slip back.

There are 3 key stages to consider –

- **Pre-admission / preventative work**
- **In hospital**
- **After discharge**

When to use it – when there is a concern that there a risk of hospitalisation or the person is already in hospital, whether everyone agrees they are planning a discharge at that stage or not.

Pre-admission

Identify common factors that were present before the crisis that led to admission, particularly what people understood about –

- The support the person was receiving
- The support the family was receiving
- The level of analysis of what we understood about how the person was coping and what was important to them
- Detailed analysis of all the factors influencing them
- Any change to support that was being asked for
- Any actions taken to change the level / focus / scope of support in direct response to information from the individual or the family
- Any changes to the person’s life that impacted on their ability to cope
- Awareness of a deterioration in someone’s situation, and the chance to plan to avoid admission
- Willingness to explore different options together

In hospital

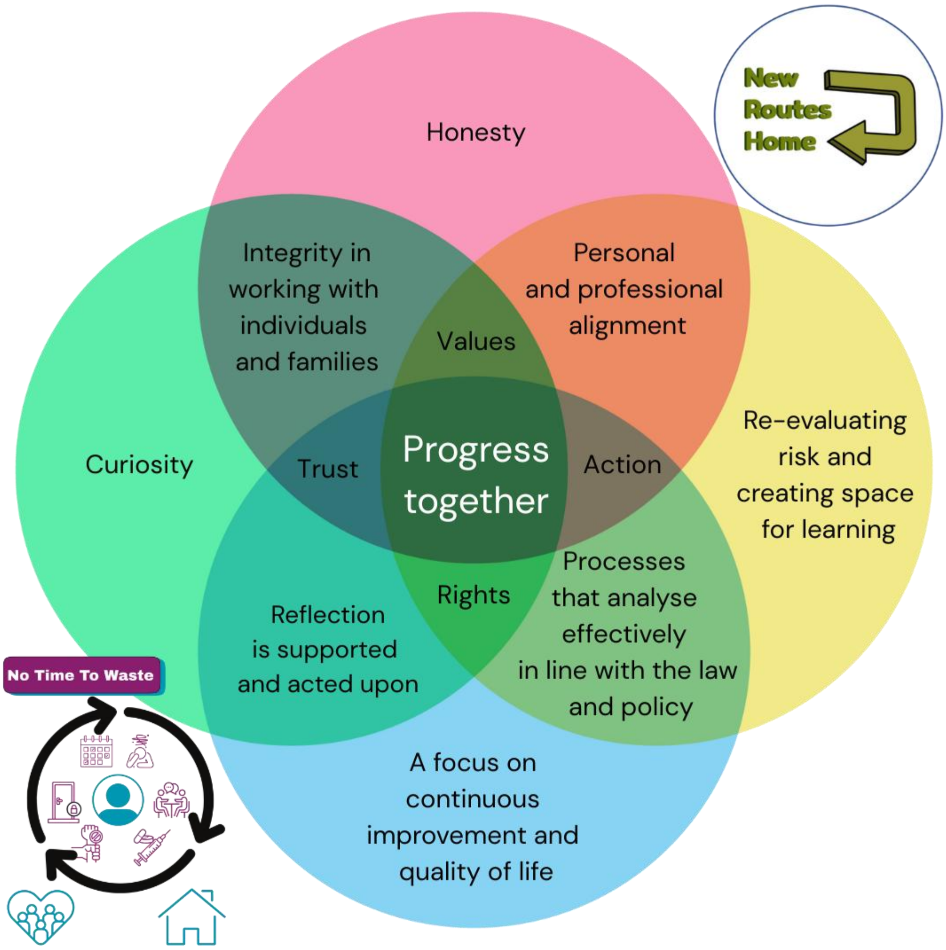
- Recording what it would take to support the person well
- Honest recording of the barriers and the scope of what has been agreed
- Active involvement and support of those closest to the person
- How learning is captured and influences practice with the person and more widely
- The extent to which the impact of the conditions as and approach impact on the person, (positive and negative)
- The ability to change and innovate when an approach isn’t working
- A focus on improving the person’s quality of life while they remain in hospital
- Supporting the person to understand what the way forward looks like
- Analysing the effectiveness of decision-making protocols
- Minimising delays and being clear about the human as well as financial cost of any lack of meaningful action
- Being proactive around seeking possible solutions, even if this extends beyond currently available options
- Being thoughtful empathetic and consistent
- A clear focus on altering the responses and support from everyone around the person, rather than expecting the person to change their behaviour while under stress

After Discharge

- Coordination of housing, planning and support
- The type of support offered and its suitability
- The follow up to make sure things are working as planned
- Reviewing and proactive planning based on who the person is, not on solely managing behaviour
- How we are learning and adapting

Reflecting and Learning Together

Which of the following statements aligns closest to what is happening now? Are there any elements that stand out? Are the actions in line with the aims listed below? If not, where are we drifting?



Pre-Admission

Statement 1

The professionals decide on the support and any interventions based mainly on the behaviours the person shows, and the focus is on minimising ones that have a negative impact on the person or others. There will tend to be little focus on measuring the person's satisfaction with their life, and how changes have impacted on them. When attempts to limit access to situations that the person is finding difficult do not result in reduction behaviours of concern, there will be focus on further restrictions on the person's routine, where they stay, and the nature of support. Medication will likely be discussed early on. Even if changes in our approach or expectations don't lead to noticeable improvements, this won't prompt a change in direction. Instead, planning is more likely to focus on maintaining safety by enforcing rules and limiting freedoms.

Statement 2

The person has had access to some support; we can clearly identify what that is and how effective it has been. Allocation of support follows local eligibility criteria, which is escalated according to local protocols. Any gaps in service have been clearly and honestly recorded, with a risk assessment of the potential impact of further action vs inaction, including any potential escalation to admission with associated costs factored in.

Any changes to this level of need are tracked in reviews. There is clarity that the person and their family is receiving the support they are entitled to, any gaps in provision acknowledged.

The person and their family receive information about how assessments have been carried out and are able to challenge them if they feel there are mistakes.

Statement 3

Person Centred Planning has been carried out in a meaningful way, involving the most important people and identifying a range of important aspects in the person’s life. This has helped empower them and those around them to feel in control, have dreams and hopes for the future, and a clear sense of how everyone would work together in a Strengths Based, Trauma Informed way whilst acknowledging and making plans for support around areas of difficulty.

Discussions have focused on staying true to the things that matter to the person, with anything that gets in the way flagged and all efforts made to explore ways to make sure problems do not escalate. There is a focus on outcomes not on services, with trust, important relationships and structure and routines that make sense to the person prioritised.

Any changes to need are followed up quickly without the need to wait for a formal review, with proactive solutions sought from all involved, even if these involve expanding our current practice. Learning is shared between everyone involved, and points from the person and their family are treated equally to professional viewpoints.

There is a focus on learning together and developments are actioned quickly, with minimal delays.

There is a willingness to be honest in identifying the potential consequences of not providing the right support.

In Hospital

Statement 1

The person is viewed in terms of their “presentation” with limited analysis of the effects of the environment. The focus is on managing risk and unwanted behaviour through limiting access to activities and locations that have involved difficulty in the past or cause concern for staff due to the lack of ability to control the environment. The professionals decide on the support and any interventions based mainly on the behaviours the person shows, and the focus is on minimising ones that have a negative impact on the person or others. There will tend to be a lot less focus on measuring the person’s satisfaction with their life, and how changes have impacted on them. When attempts to limit access to situations that the person is finding difficult do not result in reduction behaviours of concern, further restrictions on the person’s routine, where they stay and the nature of support will be the areas focussed on.

Medication will be likely to be discussed early and even if there are no positive signs from changes to what we do or expect from the person, that will not trigger change of direction, more likely planning will double down on the issues of maintaining safety through compliance with rules and reduced freedoms.

Recording will feature hospital-based experience and interpretation and less balance of who the person is.

Meetings can be held, or changed at short notice, not always with the person or their family. Information is developed by Professionals and then shared rather than co-produced.

Connections to family and friends are often the first thing to be withdrawn in the event the person is struggling.

Statement 2

There is focus on achieving progress towards discharge through a combination of planned input on the person’s skills, managing unwanted behaviours, and creating space for altering the routine and environment to better meet the person’s needs. The person and their family receive information about how assessments have been carried out and are able to challenge them if they feel there are mistakes.

There is honest recording of concerns and acknowledgment of where the environment or limits on support methods are likely to impact on the person’s wellbeing and quality of life.

It can be difficult to translate that into substantial change but there is broad agreement about the scale of the gap between what we have and what we need.

Connections to family and friends are seen as important and any impact on contact is minimised.

Statement 3

Everyone tries hard not to take positions and instead looks at the evidence in a thoughtful, unbiased way, even if it shows we need to change. We start by analysing the gap between what the person would want / finds important and where they are now. We make the effort to change our approach to reduce further stress and trauma and see how that impacts on the person’s trust. We don’t put markers that the person must achieve before discharge, instead we make sure we clearly prepare the person for each stage of the transition and encourage feedback on anything we can do to improve our support.

Progress is measured in how we are working together and improvements to our understanding and the person’s quality of life rather than simply changes in the person’s behaviour.

Connections to family and friends are protected, with extra effort given to finding solutions if access becomes difficult.

After Discharge

Statement 1

The person is only moved to an environment that can mimic most of the environmental controls and staffing responses that occur in the hospital, regardless of evidence this is working for the person or the staff supporting them. The person must achieve safety / risk based targets in this structure before reductions in staffing or new activities are considered safe to try. Often this will involve waiting to do many things the person finds important to their wellbeing. Assessments and meeting notes follow the medical model of disability and focus on how the person has responded in the clinical environment without the context of the whole person, their strengths, and their social needs. Families’ power to influence this is minimal. Even if the person is continuing to deteriorate, there may be little willingness to change direction.

Statement 2

There is a balance of need to fulfil the expectations of hospital and what the person needs in the community. Many factors will be discussed from the person and the family’s point of view as well as Professionals, however most of the time, it is likely that the traditional approach from Professionals in this situation will still be the one chosen most of the time, with minor adaptations based on what others have said. This approach has genuine attempts to engage and change, but can often struggle to get everyone onboard when significant change is suggested.

Statement 3

The person is at the centre of all decisions, at every point of decision making we ask –

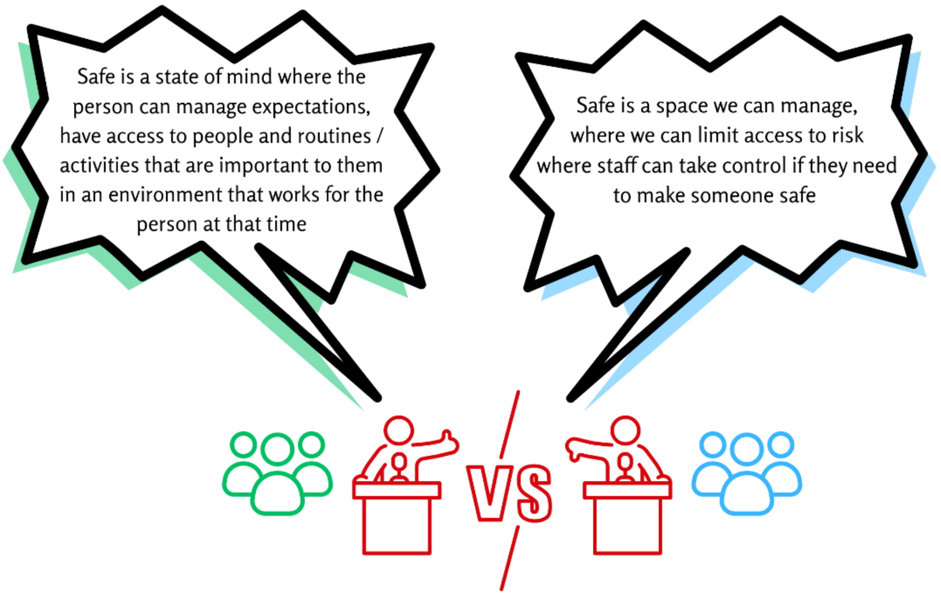
- What are we doing to be consistent?
- How does the person understand the process by which we have the confidence to move forward?
- How do we change, not expect the person to have to change?
- How do we continue to acknowledge the trauma, past and present that could derail their ability to cope?

We create safe spaces, routines and continue to explain what we do next in ways the person can test when they are not in crisis. Positions are not taken, and we fully explore all aspects of problems and potential solutions together on an equal basis. A focus on logical problem solving overcomes anxiety about change from traditional service responses, allowing confident plans to be put forward and actioned without undue pressure or resorting to formal complaints procedures.

Things that are most important to the person are not held back as final steps as a reward; they are included as quickly as possible with the rest of the plans reflecting our learning and adjusting our approach proactively but also proportionately.

Planning and Agreeing Together

Taking a position is exhausting and doesn't help us feel safe to do anything different -This does not allow for trust and learning

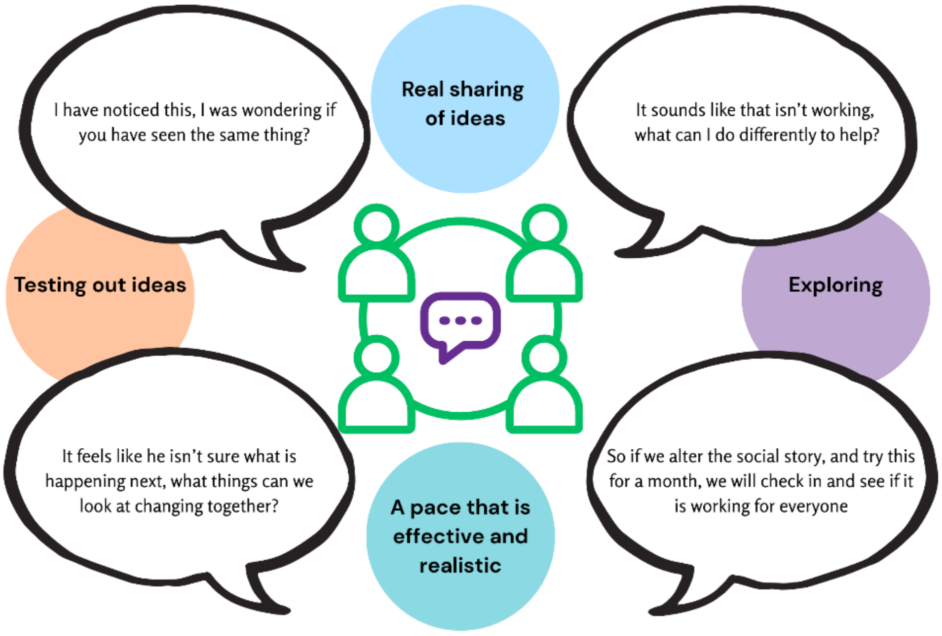


Safe is a state of mind where the person can manage expectations, have access to people and routines / activities that are important to them in an environment that works for the person at that time

Safe is a space we can manage, where we can limit access to risk where staff can take control if they need to make someone safe

We are all of equal value and the ability to explore ideas together without shutting down alternative approaches will create options that can be incredibly positive. This does not mean being irresponsible. If anything, you need to be more robust in your planning to work how many variables can affect it and everyone stays confident. Create a space where people have the chance to explore options together, minimise jargon, use language that describes the behaviour.

Creating a space where we can explore ideas and feel safe is one of the most important aspects of this process.



I have noticed this, I was wondering if you have seen the same thing?

It sounds like that isn't working, what can I do differently to help?

It feels like he isn't sure what is happening next, what things can we look at changing together?

So if we alter the social story, and try this for a month, we will check in and see if it is working for everyone

The more effort you put into the quality of the time, equalising participation in sharing ideas and analysing the details, the better the results. Use the template on the next page to guide your discussions.

Use your power gently, just because you are allowed to take something forward under legislation, it may not always be the best course of action.

Think about the way that decisions are made.

Is there thoughtful analysis of situations that take account of the whole person, alongside the people who know them best?

Are there opportunities to create a space to explore ideas and feel safe?

Are steps taken to equalise power, within the limitations of statutory duties?

Is it possible to do all of this in a way that is inclusive and free from jargon?

If not, what steps can you take?

The tool on the following page can be used to help you explore possible ways forward.

Making decisions together - using a reflective process
Give everyone the time to share and ask clarifying questions - explore the possible ways forward together
Don’t jump straight to actions

What is most important to the person - how do we know?

Use Person Centred Planning, gather feedback from people who know the person well

What do we feel we are getting right and why?

What are we concerned about and why?

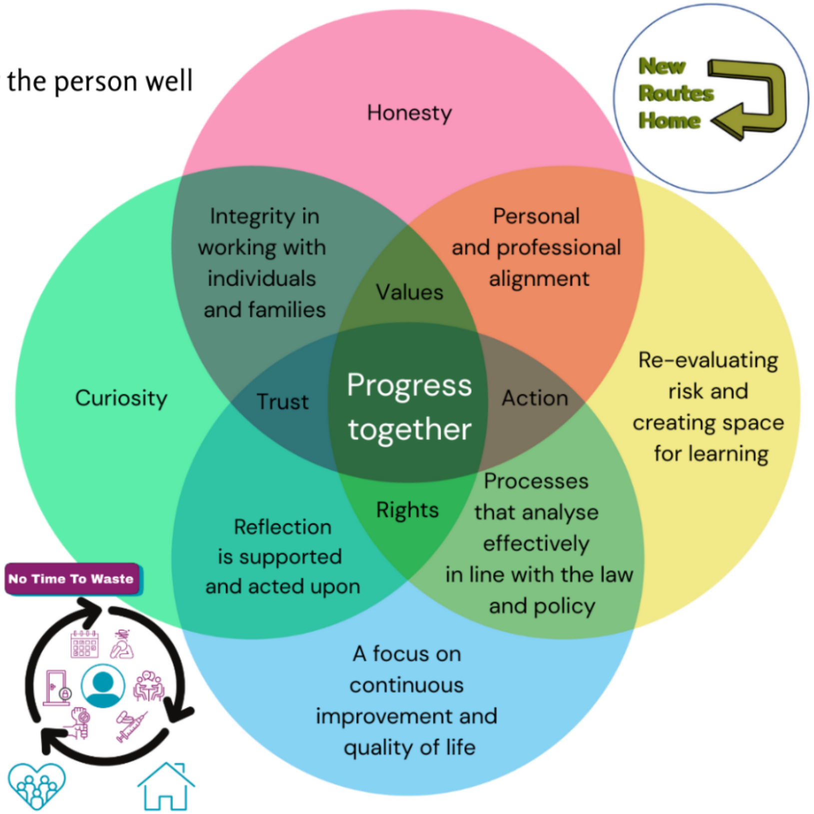
How are building on what is going well?

What evidence is there that the person is managing the current plan?

What are the opportunities and risks -

- If we make no changes
- If we make changes we think are better

Will the person see this as progress or something worrying?
Phrasing changes as positives - avoid the use of “no*



How can we make our actions predictable and based on the same principles , so the person doesn’t feel unsafe?

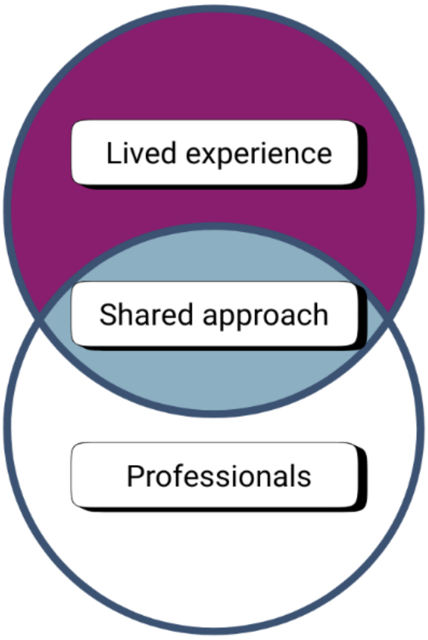
How do we build in clear steps that maximise choice and reduce the impact of any difficulties, giving a clear path back to positivity?

Evaluation

The effectiveness of this approach relies on integrity and a willingness

To create real change together. Therefore, to assess the impact we should all ask ourselves where our actions have been in line with the principles in the diagram on page 6.

We need to ask families and individuals what has changed in terms of what they experience as well as the approach. We need to learn and share together.



Did your answers and any discussions you had change the approach?

If so, how?

Did this improve things or make them worse for the person? How was that analysed?

What are you going to do with what you have learned?

Thank you for working through this process, as an individual, and as an organisation. This work is based on decades of experience in creating the right conditions to progress together, even in environments where this was not the culture or people were not of the opinion that such change was possible.

If you use this toolkit the way it is intended and trust the process you will have more equal relationships, reduced distress and better ways of supporting positive change as well as safer working conditions for staff.

You will have created spaces where people explore better community support models and better use of resources.

We check that what we are doing is working for the person, and if not we continue to change it in a planned way until we get it right

We work on the transition to community as quickly as possible recognising that expecting the person to behave in a positive way whilst under high stress is unrealistic and not in the person's interests

The next section gives some examples and resources, which should help you identify patterns that support the right approaches. We are constantly adding to the references section so please share learning with us at newrouteshome@gmail.com

Case studies / References / Resources

These are a range of quotes, documents and examples that should help reinforce confidence in the need for change, give more examples of how things were done and the learning.

Nobody that has shared these examples knows everything; we are all still learning.

Before we get into the more detailed examples related to hospitals, here is a blog post from the late Dave Hingsburger, former Director of Clinical and Educational Supports in Toronto, which illustrates a mindset that underpins where everything can start to go wrong. His books Behaviour Self, Just Say Know and Do? Be? Do? are amongst the most powerful and readable examples of human analysis of what the system is doing and reframing it in ways that make sense to everyone.

If we do not recognise the smaller losses of freedom, the compromises to what makes sense to the person, we risk building a string of smaller traumas that eventually becomes unbearable. Be aware if you are denying someone their rights or cutting corners, the human cost can be huge.

10:00 O'clock Pear

I had my 10 o'clock pear at 8 this morning. I live a lot of my life like that. The cool thing is, I get to make that call. I get to feel the regret for eating the pear now, when 10:00 hits. But right now the pleasure of the just ripe, just right, pear is still tickling at my taste buds. So, I'll cope at 10. I will. I've learned to, because I make tiny little decisions that have tiny little consequences all the time.

The other day I heard a mother say to a teen aged child with a disability, "No, you know you don't have snack until 2." It was 1:45, I shit you not. The girl, looked defiant for a couple of seconds and then sat back into compliance.

Really?

That mattered?

Really?

I know, I know, I know, that I don't know the people or the situation and there very well might have been a reason for the 15 minute delay. So don't. But can we all realize that people with disabilities are over programmed, over scheduled, over controlled and worst of all, over ruled, all the time. All. The. Time.

Simple requests get called behaviours.

Realistic disagreement gets called non-compliance.

There's a lot more names that we call people with disabilities, isn't there?

But when you live in a world where you:

Have to ask for a snack when others your age simply get what they want from the fridge.

Have to eat on a schedule you didn't set and probably weren't consulted on.

Have no flexibility on that schedule or any other schedule.

Isn't there a need for even the tiniest of rebellions?

"Speak up!" "Disagree!" "State Your Point!" I yelled all these things in my mind.

But she doesn't need my voice.

She needs her own.

I pray one day she'll have one.”

Dave Hingsburger Blog - Of Battered Aspect

Resources

Tick Tock - Scottish Human Rights Commission

“Tick Tock…”

Hospital Is Not Home - Mental Welfare Commission

Hospital is not home

Are We Heading In The Right Direction? Scottish IMPACT Network Long Stay Hospitalisation 2023 -2024 - New Routes Home

IMPACT Case Studies

Coming Home Implementation Report – Scottish Government

Coming Home Implementation: A report from the working group on complex care and delayed discharge

Assessing Risk in Institutional Settings - Easy Read Guide – New Routes Home

Assessing Risk in Institutional Settings

A New Way Home – Frances Brown and John Dalrymple

A New Way Home

Disclosure Scotland Locked In The Hospital – BBC 1 Scotland

https://youtu.be/84bjO-8lvH8

Risking a Real Life - In Control Scotland

Risking a Real Life

Counterfeit Deviance - Griffiths, Hingsburger

‘Counterfeit Deviance’ Revisited

Policy Map

INTERNATIONAL LAW

Convention on the Rights of Persons with Disabilities

Convention Against Torture and Other Cruel, Inhuman, or Degrading Treatment or Punishment

Convenant on Economic, Social, and Cultural Rights

Convention on the Rights of the Child

U.K. LAW

Human Rights Act 1998

National Assistance Act 1948

Equality Act 2010

(Whistleblowing) Public Interest Disclosure Act 1998

Criminal Justice and Courts Act 2015

SCOTTISH LAW

Social Work Scotland Act 1968

Adults with Incapacity (Scotland) Act 2000

Carers Scotland Act 2016

Mental Health (Care and Treatment) Act 2003

Community Care and Health (Scotland) Act 2002

Adult Support and Protection Act 2007

Housing Scotland Act 2014

Patient Rights Act 2011

Criminal Justice (Scotland) Act 2016

Public Bodies (Joint Working) Act 2014

Social Care (Self-Directed Support) (Scotland) Act 2013

SCOTTISH POLICY

Getting it Right for Every Child (GIRFEC)

Getting it Right for Everyone (GIRFE)

Towards Transformation

Mental Health and Wellbeing Strategy

Health and Social Care Standards

Care Programme Approach

RESEARCH AND EVIDENCE

Coming Home Report (Scottish Government)

Coming Home Implementation Report (Scottish Government)

Tick Tock (Scottish Human Rights Commission)

Challenging Social Care Decisions (MECOPP)

Hospital Not a Home (Mental Welfare Commission)

Housing for Complex Needs (Heriot Watt University)

Too Complicated to Treat (AMASE)

Accountability and the Implementation of Self-Directed Support (In Control Scotland)

Not Included, Not Engaged, Not Involved (Children in Scotland, National Autistic Society, Scottish Autism

Case studies

Case Study 1

I went to work with someone who had been described as having better verbal skills than his cognitive abilities. He was keen to impress people and would try and engage in conversations with other people and not say if he didn't understand what they were talking about. He would then feel embarrassed that people could see he wasn't following the conversation and that put more pressure on himself.

He had been returned to hospital three times in a fairly short space of time, and these had often been related to issues with relationships and alcohol.

The first time I met him I could feel his anxiety, he wanted to say the right thing and get out of hospital, and so I said to him that I needed his help. He asked how he could help, and I said I wanted him to tell me if I wasn't explaining things clearly. I gave him permission to stop me and tell me I needed to explain it better.

He visibly relaxed as he no longer had to pretend he was following the discussion if he wasn't and that I was clear it was me who needed to do better, so there was no sense that he had failed. This also set up a neutral power dynamic where he could challenge me and ask questions which made a huge difference as he wouldn't do that before.

His experience was that he would struggle with conflict and be unable to disengage from the anger and frustration, talking constantly about how unreasonable the other person was being until the Police got involved, he resisted, and he was physically restrained and then returned to hospital often soon after. This pattern had repeated, and he had never successfully managed to return to a calm relaxed state in these circumstances. It didn't seem to matter if he had skilled support or minimal discussion, it never ended well.

We identified the key factors and suggested an alternative approach. When a situation like this happens the staff member could say “I am heading back to the flat now” and start walking back. We would not discuss the incident on the way back, it was important that he didn’t feel he was being ignored but no matter how he tried to engage with us in discussion, we wouldn’t do it.

We explained to him this was what we would try and that after 20 minutes of being back at home, we would come through and ask if he was ready to talk about it. That way we would be away from the situation and the person involved. We went over this with him – this was to help keep him safe and find a better way as what had happened before wasn’t working. We were clear staff would walk in the direction of the flat but try to physically guide him, as that had been a problem in past support settings. We allowed him to check it out many times with us when things were calm, “we will do this, and this is why”.

The first time we used the approach, he followed the staff member home, was quite agitated and did try to engage in discussion a couple of times on the way back, but his anxiety did not become unmanageable. After 20 minutes, we asked if he wanted to discuss it and he was still highly anxious and not in place to be able to discuss the situation. We learned later that he had spent the 20 minutes looking at the clock waiting for it to be time to discuss it.

We said sorry we got that bit wrong, we will keep the first part the same for how we respond, but when you come home, you let us know when you are ready to speak about it. That could be 20 minutes, it could be the next day. We also said if we didn’t feel he was ready when we started discussing it, we would say so.

Through this process we were able to establish trust and successfully break a pattern of readmission through predictable, reliable support that that gave him what he needed.

When something works, it’s important to stick with it consistently. If we become complacent and stop following it, we may only then realise it was effective, because it was meeting the person’s needs and helping them navigate a difficult situation.

Case Study 2

A person with a history of trauma was coming out of hospital after spending several years in hospital. The Consultant's idea of safety was to replicate much of the hospital environment and gradually reduce restrictions. Through the work we had done with the person we identified another way. The expectation was for bars or window restrictors on his flat windows, as he had regularly climbed out of windows and been chased by the Police. We said we were going to use neither as his door was not going to be locked, we prepared him for a different set of responses from staff.

He had been frustrated at the lack of a routine that worked for him in hospital so he pushed staff as hard as he could until someone gave in. We were starting with a routine he had designed, and he had planned meetings with management, so he wasn't only listened to when there was a problem.

When he did try to run, he got to the corner and when he saw nobody was chasing him, he hesitated, the staff member had prepared for this instance and put out two cups of coffee on the picnic bench outside his flat.

An invitation and a clear way back with no loss of face. These are the ways we change years of negative patterns.

The same man also was told he had to have a member of staff in his one bedroom flat overnight to begin with. This was someone who struggled to disengage and had never ended a period of anxiety in the presence of others without physical restraint. There was a member of staff at the bottom of the stairs, connect by smart tech, but there was an insistence he would not be discharged if this was not in place.

I agreed to it for two weeks maximum as I thought it was high risk for both the individual and the staff member. The support was removed after two weeks, and he never needed that constant input in his flat overnight.

Often too much support can be dangerous as the person can't escape the interaction. More is not always safer.

Case Study 3

Someone who didn’t feel safe enough to put down his belongings and used to self-injure regularly was planning to move to the community after years in hospital. As part of the move to a 4 person group home, we organised some stays at a respite house so everyone could get to know each other. He spotted a magazine rack full of magazines. In his ward they would have been destroyed, and he gathered them all on his lap, marvelling at them.

After a while I persuaded him to put some back and just keep a few. The second week he put down his belongings and was visibly relaxed. On returning to the hospital, I passed the information to the keyworker who listened but clearly was sceptical.

The following week we had another stay, this time I requested that the key workers from all four men came along, but stay in the background, and see if they saw what I did. The man was again relaxed, feeling safe he put down his belongings. The keyworker said he would not have believed that change was possible in five years let alone two weeks.

This man had no verbal communication, he felt it was safe and despite his current living conditions and previous experience, he quickly trusted the people around him. If we don’t get the chance to show how life can be different, we will only see someone in crisis.

Feedback from Key as to what works

1. Identify the support provider and get them round the table as soon as possible – we have the experience of meeting people's complex needs within a community setting – sorry, but building based health services don't – they're not an RSL or a social care provider. This would become a barrier to finding solutions together, mitigating risks while planning to get the person a life again.
2. Recognising a distinct benefit in the 'core group' approach as it's completely focussed on discharge planning and the person's life out with the hospital setting. It also helps get the provider to the table as quicky as possible.
3. Full information sharing – all of the details known, no matter what, around risk and complexity. From here we can plan positively to minimise risks while also getting the person the life they want.
4. Having all of the right people and stakeholders involved both with a knowledge of the person in hospital, but also in their community – and the supports which will be available from the various services. So let's also have health and social work staff included from community learning disability teams alongside the hospital staff as they can make direct offers of the support they know they can provide alongside the support provider.
5. Ensure we have the decision makers engaged in this journey e.g. Consultant Psychiatrists, Clinical Psychologists, commissioners/funders. If they are not participating, it risks being a 'talking shop' with no action.
6. Providers will involve PBS practice leads alongside managers of services which can shape the support and development of staff teams, early risk assessments, housing briefs etc.
7. Quickly move to develop a person centred housing brief – I'd describe this as a mini ELP for the person's house and home – what's essential to have/not have, non-negotiables for getting the house right – areas to look for/avoid – closeness of other neighbours, any size/space needs (indoors/outdoors), any safety/security needs, including possible 'safe space' needs for the

person, or for staff to withdraw to if the person is having a crisis – features which help sustain the person at home, regardless of any challenges. The earlier this housing brief can be developed, the earlier the house search can start, and RSL's do what they do well.

8. Considering any more significant interventions – physical/environment, with all parties and having the correct protocols/training/joint risk assessments in place for these features and any other known risks. Any more 'radical' measures required e.g. our experience of having locked away ligature cutters available for staff, blood spillage kits and training in cases of known, severe self-harm etc. in order that more radical interventions can be made to keep the person safe in times of crisis, and until emergency services can intervene.
9. Starting lead in work with recruited and identified staff/managers as early as possible, and out with the hospital environment – the support won't be provided in hospital! This starts building relations and informing support plans and risk assessments.
10. Last point – ensure openness/honesty (some early terms of reference or ground rules/understandings would be good) around checking in if we're all on the same page – and being ok with brave or difficult conversations.

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New Routes Home is a collaboration of people with paid and lived experience, who meet regularly to share practice and advocate for change.

Anyone with an interest in deinstitutionalisation is welcome to join.

If you would like to know about New Routes Home email newrouteshome@gmail.com visit our website https://newrouteshome.wixsite.com/scotland

IMPACT is the UK centre for implementing evidence in adult social care.

Working across the four nations and with co-production at its heart, they draw on insights from research, lived experience, and practice knowledge to make a difference to front-line services, and to people's lives.

In Control Scotland is a small Scottish charity that works collaboratively for a fairer system of social care support.

They are the host organisation for New Routes Home. You can find out more about In Control Scotland on our website: www.in-controlscotland.org